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ABSTRACT

The fourth in a series on deinstitutionalization of individuals with developmental disabilities in Ohio, the paper concentrates on the contributions of formal and informal supports. Following a review of basic planning principles, formal support services necessary for planning community-based services for persons with developmental disabilities are listed, including transportation, service coordination, income maintenance and budgeting, mental and physical health services, and legal services. Possible problem areas facing systems shifting from a categorical to a generic resource based approach are noted. Informal supports, such as neighbor or family help, group religious activities, and neighborhood clubs are discussed, and their value to families with developmentally disabled members is emphasized. Obstacles to development of informal supports are noted, and the importance of helping disabled persons develop and maintain informal support relationships is underlined. A series of recommendations regarding formal and informal support systems concludes the report. (CL)

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POSITION PAPER NO. 4

Promoting Quality Community Living Through Formal Support Services and Informal Supports

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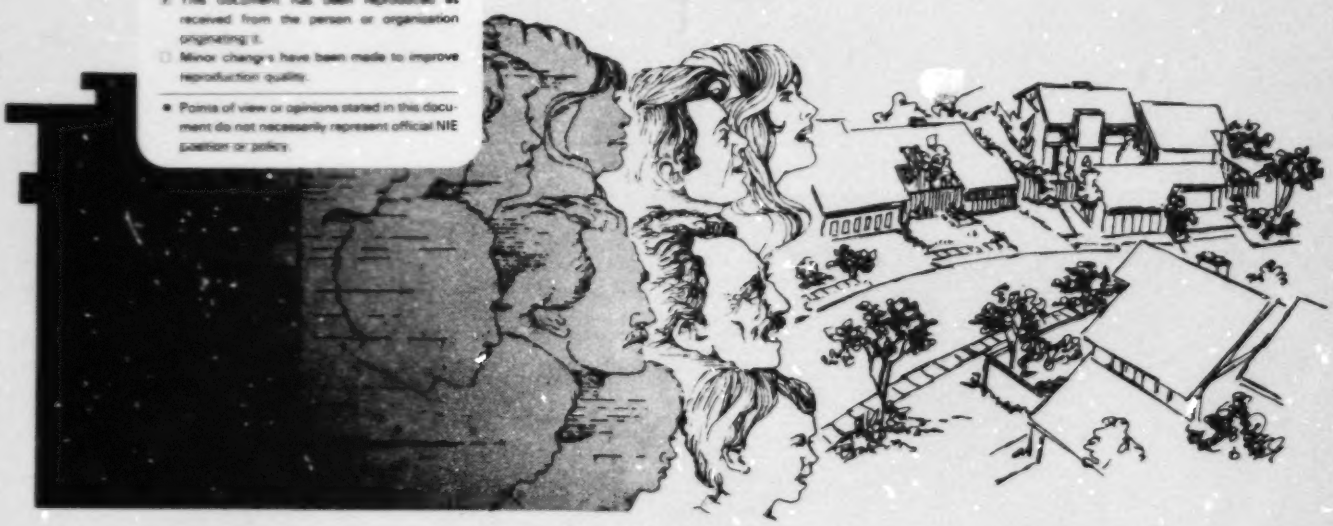

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Promoting Quality Community Living Through Formal Support Services and Informal Supports

Prepared by
The Prevention of Institutionalization Subcommittee
Deinstitutionalization Task Force

Ronald E. Kozlowski, Project Coordinator
Cheryl Phipps, Subcommittee Chairperson
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The contents of this paper reflect official policy and positions of the Ohio Developmental Disabilities Planning Council.

December 1983

"PEOPLE WERE MEANT TO COMPLEMENT EACH OTHER. WHERE I AM STRONG, YOU MAY BE WEAK. AT POINTS WHERE YOU EXCEL, I MAY BE ALL THUMBS. AND THE ULTIMATE TRAGEDY TAKES PLACE WHEN I REJECT YOU BECAUSE OF YOUR HANDICAPS AND YOU REJECT ME BECAUSE OF MINE. THEN WE LIVE APART . . . AND WE DIE APART. WE DIE WITHOUT EVER REALLY KNOWING EACH OTHER OR EXPERIENCING THE RICH CONTRIBUTIONS EACH COULD HAVE MADE TO THE OTHER'S LIFE."

Robert Perske
1980

This paper reflects the official position and policy of the Ohio Developmental Disabilities Planning Council. The development of this paper was supported by funds made available through a grant from the Ohio Department of Mental Retardation and Developmental Disabilities, authorized under P.L. 95-602 to further the attainment of the goals and objectives of the Ohio Developmental Disabilities Planning Council.

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PREFACE

Changes in the philosophy of services and a growing concern for the rights of persons with developmental disabilities have led to a national deinstitutionalization movement. Thus, the service system for Ohio's citizens with developmental disabilities is in a period of transition as the state moves from an institution-based to a community-based service delivery model. Although the deinstitutionalization movement has increased the move toward community-based services, numerous constraints continue to challenge this effort. With the transition in progress, the development of long- and short-term service development plans is critical to the evolution of a cohesive system that uniformly provides appropriate and adequate services. Identification of the nature and shape of the desired service system, the recognition of existing and potential constraints, and the development of an effective planning process must occur to assure that quality services are available now and in the future.

It is within this context that the Ohio Developmental Disabilities Planning Council created the Deinstitutionalization Task Force Project. The purpose of the project was to establish and provide staff support to a Deinstitutionalization Task Force, which was formally constituted in March 1981. The Task Force, composed of representatives from various agencies and consumer groups (see inside back cover), was charged with the responsibility to identify major issues related to deinstitutionalization and to develop recommendations for increasing the availability of appropriate services to persons with developmental disabilities.

Given its charge, the Task Force had two major options in terms of where to focus its attention: (1) on the nature or structure of the service system or (2) on the service process. Because of the scope and complexity of the issues related to deinstitutionalization, the Task Force decided to focus on the nature or structure of the service system. This approach was chosen because (1) an appropriate structure is a necessary condition for the development of quality, appropriate services and (2) many process guidelines and safeguards are already present in rules and regulations. By focusing on the structure of the service system, the Task Force could then develop a plan containing: (1) a broad outline of the proposed service system and (2) a broad outline of proposed planning strategies.

The Task Force considered this option as most consistent with the Developmental Disabilities Planning Council's advocacy function, in that the development of a broad outline of the proposed service system facilitates systemic change. Long-range service goals define how things "ought to be" and can be used to guide short-term transition planning.

The Task Force initially sought to identify the various legal and philosophical principles in the field of developmental disabilities and to define with a high degree of clarity the actual issues surrounding deinstitutionalization. These deliberations were based on experiences in Ohio and augmented by the experiences of some of the more active state programs outside of Ohio. The basic concepts that emerged were used then to guide the planning process.

This led to the second step, which was to apply these concepts to a service system for persons with developmental disabilities. The Task Force selected the following broad areas in which to concentrate its efforts: (1) the role of institutional services (2) residential services (3) adult services (4) informal and formal supports, and (5) administrative structure and finance. To provide broad-based professional and consumer input in addressing these general topical areas, a subcommittee structure was established. The following subcommittees were constituted by the Task Force:

- o Institutional Services Subcommittee
- o Community Services Subcommittee
- o Prevention of Institutionalization Subcommittee
- o Finance Subcommittee

This structure essentially provided a two-tier review process. Each subcommittee was charged with the initial development of a position paper on a selected topic. The Community Services Subcommittee was charged with initial development of position papers on two topics. The papers were then all submitted to the Task Force for review and/or modification, and subsequently adopted as official position papers of the Task Force. The five position papers provide statements of program philosophies and service strategies that can be used to develop quality services for persons with developmental disabilities. Each position paper contains a series of broad recommendations that the Task Force believes should be used in developing specific implementation plans.

The Task Force believes that the position papers describe a realistic direction for Ohio's service system and should be used as roadmaps for developing quality services for persons with developmental disabilities.

Papers in the series include:

Position Paper No. 1:	THE FUTURE OF INSTITUTIONAL SERVICES IN OHIO: Do We Need to Plan for Institutional Services?
Position Paper No. 2:	RESIDENTIAL SERVICES IN OHIO: The Need to Shift from a Facility-Based to a Home-Centered Service System
Position Paper No. 3:	FUTURE DIRECTIONS IN ADULT SERVICES
Position Paper No. 4:	PROMOTING QUALITY COMMUNITY LIVING THROUGH FORMAL SUPPORT SERVICES AND INFORMAL SUPPORTS
Position Paper No. 5:	FUTURE DIRECTIONS IN ADMINISTRATIVE STRUCTURE AND FINANCE: PREREQUISITES FOR COMMUNITY-BASED SERVICE.

Nisonger Center
The Ohio State University

Ronald E. Kozlowski
Project Coordinator

ACKNOWLEDGMENTS

The Deinstitutionalization Task Force Project was originally established through a letter of agreement between the Ohio Developmental Disabilities Planning Council, The Department of Mental Retardation and Developmental Disabilities, and the Ohio State University Research Foundation (Nisonger Center) to identify issues and develop recommendations relative to deinstitutionalization in Ohio. The products of the Task Force are the result of a collaborative effort by various individuals, representing a variety of organizations and agencies, who participated on the Task Force or its subcommittees, or otherwise provided assistance in developing the various position papers. Forty-two individuals, representing thirty-three organizations and agencies, contributed to the development of the five papers. Appreciation is extended to those individuals, who graciously gave their time, patience, and expertise.

A special mention is made of the sincere efforts that were put forth by Dr. Jerry Adams, who conceived the project and devoted tremendous personal energies toward making project activities viable. Succeeding Dr. Adams, Dr. Denis Stoddard also devoted much personal energy in supporting the project. Dr. William Gilbert and Dr. Henry Leland (Co-chairpersons) guided the Task Force through its deliberations and saw to it that the Task Force completed its tasks. Appreciation is also expressed to the Ohio Developmental Disabilities Planning Council for recognizing the significance of this project and providing funding for its activities, and adopting the position papers produced by the Task Force as official policy and position statements of the Council.

FORMAL AND INFORMAL SUPPORTS

Formal support services and informal supports assist persons with developmental disabilities in ways that maximize the person's:

- o Independence and human dignity
- o Presence and participation in community life
- o Status as a valued community member
- o Potential for growth and development

Formal support services and informal supports are important components of a community's plan to ensure an adequate quality of life for persons presently residing in or returning to the community, and in preventing the need for institutionalization.

FORMAL SUPPORT SERVICES DEFINED

Formal support services are those organized services provided by a variety of agencies/providers that assist a person to live in the community—transportation, dental and medical care, adult basic education, mental health services, recreation/leisure time activities, etc. Some of these services are typically provided by agencies that serve only persons with developmental disabilities, such as County Boards of MR/DD, or by generic service providers. Historically, most support services to persons with developmental disabilities have been provided in segregated settings by service agencies that provide services only to persons with developmental disabilities. However, widespread acceptance of the normalization principle has led to an increased demand for the utilization of generic service providers (McCord, 1982). Generic service providers are those agencies that offer services to the general public, such as mental health agencies, hospitals, etc.

INFORMAL SUPPORTS DEFINED

Informal supports are support networks such as families, friends, neighbors and peer groups, or organizations such as churches, schools, work groups, and clubs that offer friendship and assistance in problem solving and obtaining needed assistance. Often, interactions in these support networks reflect a reciprocal relationship. Persons with disabilities receive support and, in turn, offer friendship and help.

Informal supports operate on a one-to-one, as well as a group level. On the one-to-one level, they are "natural" care-giving efforts that generally develop and continue without professional intervention. Supportive relationships may exist between a friend and neighbor, nephew and uncle,

pastor and parishioner, landlord and tenant, or among co-workers.

Group forms of informal supports are usually more organized than are one-to-one supports. Sometimes groups are organized with the help of professionals; other times they develop without such intervention. Such groups help persons with disabilities see that they are not alone and that others share their concerns and needs. Other groups such as clubs or neighborhood organizations may not be organized for self-help purposes. But even in these groups, participation becomes an important element of an individual's informal support network, providing help and sustenance.

Traditionally, the development of comprehensive services for adults with developmental disabilities has centered on providing residential and day program services. The focus has been on where a person may live or work in the community. However, a person may receive appropriate residential and day program services and still experience major deficiencies in the quality of his or her life. For example, numerous studies have shown that, although persons with developmental disabilities may live in physically integrated residential programs, seldom are they socially integrated into the community; they rarely interact with persons outside their residence or outside a network of other persons with disabilities (Moreau, Novak, & Sigelman, 1980). Moreover, the lack of formal support services has been cited frequently as a major impediment to meeting the needs of persons with developmental disabilities in the community (Bruininks, Williams, & Morreau, 1978; Savage, Novak, & Heal, 1980; Scheerenberger, 1976). It is becoming increasingly evident that the lack of formal and informal supports not only adversely affects the quality of life of persons living in the community, but also increases the likelihood of placement in more restricted residential and day program options than are needed to meet the person's needs (Biegel & Naparstek, 1982; Gollay, 1976; Heal, Sigelman, & Switzky, 1980).

BASIC PLANNING PRINCIPLES

A necessary first step in the development of formal support services and informal supports for persons with developmental disabilities is the delineation of principles upon which the support system must be built. These principles, which reflect basic philosophical and legal concepts in the field of developmental disabilities, should guide the planning, development, and implementation of support services and informal supports.

LEAST RESTRICTIVE ALTERNATIVE

Attaining the least restrictive alternative requires that services and supports be provided in the most age and culturally appropriate manner for meeting the person's needs for supervision and training, without imposing unnecessary modifications or denial of personal rights. A further consideration is that the selection of particular services and supports must be based on the person's needs and wishes—not just on the options currently available.

Appropriate application of this principle requires that formal support services be provided in the community through the usual, generic sources. For example, adult basic education should be available through agencies that typically provide such services to all persons in the community, not just available within the confines of a sheltered workshop or group home. Likewise, rather than establishing separate transportation services that restrict the frequency, time, and mobility of persons with disabilities, regular transportation systems should be utilized to accommodate the needs of persons with disabilities. Mental health services generally available in the community should not be denied because they are deemed inappropriate for persons with developmental disabilities—nor provided on a limited or segregated basis—but should be available to all individuals in the community based on their need for such services. Rather than promoting total dependence upon the service system, opportunities to develop informal supports in natural environments should be encouraged. A restricted environment limits the development of informal supports. Physically and socially integrated working, living, and training environments provide increased opportunities for developing informal supports.

RIGHT TO SERVICES

Right to service concerns the right of persons with disabilities to services or supports that promote growth toward increased independence and competence. A variety of community support services are needed to meet the multiple needs of persons with developmental disabilities. While it may be possible for persons to benefit from congregated and segregated programs, it is questionable whether such programs provide an appropriate service environment. The segregation of persons with developmental disabilities in physically and socially segregated settings cannot contribute positively toward enhanced independence and competence. Most individuals rely on informal support networks in their daily lives. These informal supports are even more important to persons with disabilities.

NORMALIZATION PRINCIPLE

Normalization refers to ". . . the utilization of as culturally valued means as possible in order to establish and/or maintain personal behaviors, experiences and characteristics that are as culturally normative or valued as possible" (Wolfensberger, 1980). This principle calls attention to (1) what the service/activity achieves for those it serves (the "goals") and (2) how the program/activity achieves these objectives (the "means" in the definition).

Appropriate application of the normalization principle results in the development of formal support services that ensure as much as possible the person's presence and participation in typical community life. Support services should be obtained from community agencies that serve the general public. As Wolfensberger points out, ". . . maximal integration of the perceived or potential deviant person into the societal mainstream is one of the major corollaries of the principle of normalization." (Wolfensberg, 1972). The President's Panel on Mental Retardation also called for using generic services, those available to the general public, whenever possible to meet the multi-faceted needs of persons with developmental disabilities (President's Panel on Mental Retardation, 1962).

Application of the normalization principle also should result in an increased interest in helping persons with developmental disabilities develop informal support networks. Just as most of the general public rely on informal supports in their daily life, so do persons with developmental disabilities. Informal support networks should be created and maintained by persons with developmental disabilities (Biegel & Naparstek, 1982).

EQUAL JUSTICE

Adherence to the principle of equal justice requires that all persons with developmental disabilities be provided services and supports that will allow them an equal opportunity for growth and development. The principle of equal justice requires that long-range plans be based on the assumption that all persons can participate in community life. It is a denial of equal justice if persons with developmental disabilities are excluded from community generic services such as recreation, mental health, or adult basic education because of their disability—if such services or activities are available to other persons in the community. It also is a violation of the concept of equal justice if individuals are hindered in developing informal supports through use of unnecessarily restrictive or segregated service strategies that prevent the development of such supports. If informal supports are important to nondisabled persons,

they are probably even more important to persons with disabilities.

RESPECT FOR HUMAN DIGNITY

Most persons have personal characteristics and competencies that are valued by others. Also, they can advocate for themselves and are therefore usually afforded at least a minimum of dignity and respect. Except in very limited ways, persons with severe handicaps cannot gain the same degree of dignity and respect by their own actions. It is therefore extremely important that they be treated with respect and served in settings that are as positively valued as possible.

Persons with severe handicaps should not be served in devalued segregated programs, but should be served as much as possible in a normal community setting. For example, segregated "special" recreation and leisure time activities usually do not increase the perceived value of the individual. Every effort should be made to ensure that services are provided in a manner and setting that is positively valued by the community. Services should enhance the status of persons with developmental disabilities (as well as society's perception of them), and enable persons with developmental disabilities to assume more normal societal roles. Application of this concept also requires that persons with developmental disabilities actively participate in planning decisions that affect the delivery of services, as well as in any other decisions that affect their lives. Agency policies should allow persons with developmental disabilities to participate in such decisions, and should actively encourage and arrange for such participation.

DEVELOPMENTAL ASSUMPTION

The developmental assumption is based upon an acknowledgment of (1) life as change (all individuals, regardless of type or degree of handicap, have the potential for positive growth) and (2) development as modifiable (influenced through teaching, and by using and controlling physical, psychological, and social aspects of the environment).

Adherence to the developmental assumption requires that services and supports are designed to be growth-enhancing and supportive of learning. Until recently the assumption was that persons with severe disabilities required separate, very special services and settings for maximum growth and development. This limited application of the developmental assumption is now being challenged. A variety of research studies have shown that persons with severe

disabilities benefit from exposure to, and can be effectively taught in, more normal typical settings (Martin, Rush, & Heal, 1982). The focus of services and supports should be shifted from the person's disability to the person's functioning within a social environment.

Application of the developmental assumption requires that community-based training include training in the skills needed to use community resources and to develop and maintain interpersonal relationships.

EFFECTIVENESS AND ECONOMY

Recent research shows that it is very important, especially for persons with severe and profound handicaps, to participate in training programs that are as similar as possible to normal community settings (Martin, Rusch, & Heal, 1982). This is especially important for persons with mental retardation because of their difficulty in generalizing from the original learning environment to other settings.

Continued dependence upon segregated programs is unrealistic. Certainly, there are practical considerations that must be taken into account:

- Economic considerations argue against the continued development of segregated programs and services (duplication of services, cost of providing a particular service across specific population groupings, etc.).
- Trained personnel often are not available to staff the wide variety of different segregated programs that would be needed.
- No one agency or program has the resources to provide the necessary range of services to meet the many needs of persons with developmental disabilities.

Equally important, however, is the fact that in the absence of a full range of formal support services, persons with disabilities are apt to be placed in more restrictive, and costly, programs than are necessary to meet their needs. Likewise, the absence of informal support networks fosters a greater dependence upon the service system, resulting in a more likely need for greater "system intervention," especially in times of crisis (Albee & Jaffe, 1981; Gerhard, Dorgan, & Miles, 1981).

COMMUNITY-BASED NETWORK

The Prevention of Institutionalization Subcommittee identified three basic components to a community-based network, which would support the presence and participation in community life of persons with developmental disabilities:

- Residential and work (or work training) program

- Formal support services
- Informal supports

Residental and work (or work training) programs deal with where people live and what they do during the day. Position Paper No. 2 and Position Paper No. 3 of the Deinstitutionalization Task Force contain analyses of issues affecting the development of residential and work-related programs.

Formal support services such as transportation, dental services, leisure time/recreation programs, and medical services, enable a person to live effectively in the community. Because of the multiple needs of persons with developmental disabilities, a full range of support services must be available. Lack of such services is frequently cited as a major reason for placement in a more restricted setting than is necessary to meet a person's needs. Equally important, the success of residential and adult services is highly dependent upon the availability of support services in the community.

Informal supports such as families, friends, neighbors, churches, schools, work groups, and clubs are the third major component of a community-based network for persons with developmental disabilities. Informal supports and networks assist a person with social integration into the community, thus increasing the quality of the person's life and decreasing the need for "service system" intervention.

The variety of services and supports needed by persons with developmental disabilities is shown in figure 1. The interrelationship of the three components of a community-based network is also reflected in figure 1. This interrelationship can be seen in two areas:

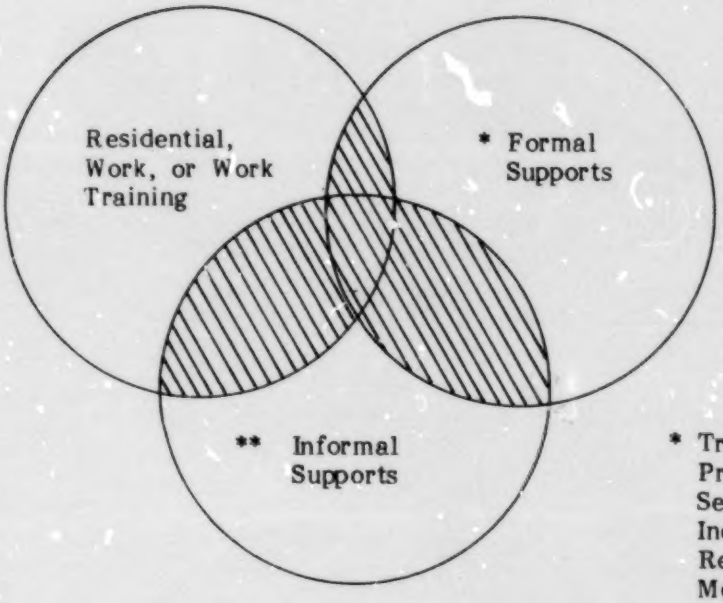
- Informal supports come from a variety of sources such as where a person lives and works, and from people with whom they interact.
- Success in each component depends to a degree on the appropriateness of the other two components.

FORMAL SUPPORT SERVICES

The Subcommittee identified the following formal support services as essential to planning for community-based services for persons with developmental disabilities. The list is not intended as a comprehensive list of all formal support services, but as a list of major services that generally are required to meet the needs of persons with developmental disabilities. It is important to note that most of the services

Figure 1

MAJOR COMPONENTS OF COMMUNITY-BASED NETWORKS



** Self-help/mutual support groups
Social supports in workshop
Neighborhood supports
Religious supports
Family supports
Friendships

* Transportation
Protective services
Service coordination
Income mainentance and budgeting
Recreation/leisure time activities
Mental health services
Physical health services
Specialized therapeutic intervention
Crisis intervention
Adult basic education
Legal services
Family support
Homemaker
Behavior modification

on the list are not new. Many such "needs" lists have been developed in the past, but only "bits and pieces" have ever been implemented. The challenge is not to gather more data about needs, but to find ways to provide these services through positively valued generic agencies.

- o Transportation: public or private services that enable persons with developmental disabilities to travel around the community in which they live and work (whenever possible, these services should involve existing public transportation systems)

- o Protective Services: range of socio-legal services that help protect and facilitate the exercise of individual rights (such services assist persons with developmental disabilities in obtaining the maximum independence possible, while appropriately protecting them from exploitation, neglect, or abuse)

- o Service Coordination: linking and coordinating segments of the service delivery system to ensure the availability of a comprehensive array of services

- o Income Maintenance and Budgeting: skill training and assistance to individuals in acquiring, using, and planning for basic necessities of life such as food, clothing, shelter, and money

- o Recreation and Leisure Time Activities: activities designed to (1) help meet specific needs in self-expression, social interaction, and entertainment; (2) develop skills and interests leading to enjoyable and constructive use of leisure time and; (3) improve well-being

- o Mental Health Services: services that assist persons with developmental disabilities in forming harmonious relations with others, and in participating or contributing constructively to changes in their social and physical environment

- o Physical Health Services: a full range of medical, dental, nutritional, pharmacy services that provide for health needs. Included are needs common to all persons, plus the special needs that may arise from problems associated with developmental disabilities

- o Specialized Therapeutic Interventions: a full range of occupational therapy, physical therapy, speech therapy, and psychological services

- o Crisis Intervention: a variety of services, including counseling, that are available on an emergency basis

and are immediately responsive to individual and family needs at times of extreme stress

- o Adult Basic Education: continuing educational opportunities for adults in areas such as communication, social skills, money management, and independent living skills

- o Legal Services: a combination of legal and advocacy services that protect the individual's civil and personal rights and prevent victimization

- o Family Support Services: a variety of services such as family training, family planning, counseling, respite, special therapy, adaptive equipment, home renovation, home health care, homemaker, and day care services—all supporting the maintenance of a person in his or her own family setting

- o Homemaker Services: chore and/or personal care services that must be available for a person with developmental disabilities to enable him or her to live as independently as possible

- o Behavior Management: efforts to modify maladaptive or problem behaviors and to replace them with behaviors that are more adaptive and appropriate

Use of Generic Resources

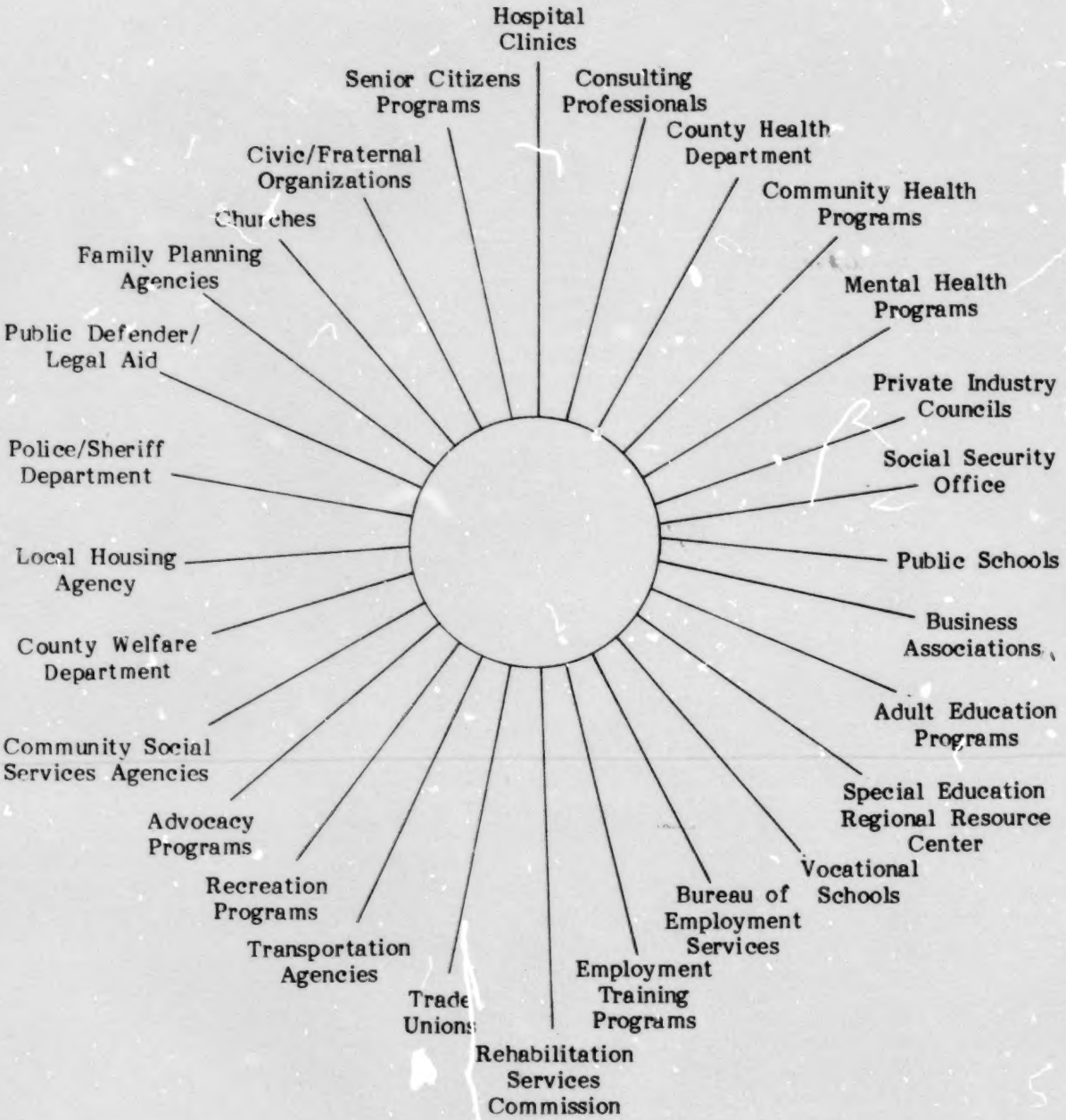
Local planning efforts should seek to optimize the use of generic community resources in providing support services to persons with developmental disabilities. An inherently valuable aspect of community life will be lost if such services are provided only in segregated settings. A major challenge in developing comprehensive community services is the ability to use a full array of generic community resources and services. A listing of the variety of community generic resources usually available at the local level is shown in figure 2.

Possible Problem Areas

It is important to recognize the danger of diminished or lost services that can occur as the system shifts from a segregated, or categorical, approach to one based on generic resources. Experience has shown that in the absence of appropriate planning and service development, generic agencies may inappropriately serve and, in some instances, even deny services to persons with developmental disabilities.

Figure 2

LOCAL GENERIC RESOURCES



Some of the problems involved with a shift to the use of generic services include (Gettings, 1981):

- o Access problems such as ambiguous eligibility requirements and informal denials of service
- o Untimely exclusion and termination of services, resulting from inappropriate outcome measures
- o Inadequate services resulting from inability of the overall "system" to deal with unique needs of persons with developmental disabilities
- o Lack of mechanisms to coordinate effectively the array of services needed by persons with developmental disabilities
- o Increased competition for scarce public funds
- o Lack of a coherent set of policy goals at the federal and state levels for providing services to persons with developmental disabilities

A strong emphasis on planning and monitoring of service provision will be necessary at the state and local levels to ensure that the needs of persons with developmental disabilities are met.

Consumer Participation

The Subcommittee also calls attention to the responsibility of local communities and agencies to ensure that persons with developmental disabilities participate in planning decisions that affect the delivery of services, as well as in any other decisions that affect their lives. Persons with developmental disabilities should not only be provided the opportunity for, but also should be encouraged and assisted in participating in such decision-making.

INFORMAL SUPPORTS SYSTEM

Informal supports are an important component of everyday life. Almost all individuals use informal supports in one way or another: the advice received from a family member, transportation to and from work provided by a fellow worker, assistance from a neighbor in completing household repairs, and the social interaction provided by a friend. Other types of informal supports can be more organized. For example, participation in a group religious activity, membership on a softball team sponsored by an employer, or participation in a neighborhood club are all forms of organized informal supports. Informal supports can

assist a person in problem solving, obtaining needed assistance, making friends, or creating a sense of belonging. These supports not only enrich a person's life but also provide invaluable assistance in coping with the everyday stresses of life. The ability to form and maintain informal support networks is an important factor in determining the quality of a person's life.

Importance of Supports

Informal supports are important to nondisabled individuals, but they are even more important to persons with developmental disabilities because of the increased stress in their everyday lives. Historically, persons with disabilities have often been "rejected." They have experienced rejection by family members, other citizens, the community at large, and by human service workers and agencies. Usual outcomes of being rejected include the experiences of being manipulated by people or systems, being abused or exploited, and being labeled as "incompetent." These experiences can manifest themselves in feelings of frustration—generally being unable to make decisions concerning their own lives. Results of this frustration can lead to such things as lashing out, withdrawal and, most significantly, rejection of oneself (DeFazio & Pealer, 1981).

Unlike nondisabled individuals, persons with developmental disabilities seldom have freedom to choose the kinds of supports they need. Most often they have to depend exclusively upon the "service system" for their supports. This dependence has made persons with developmental disabilities more subject to influence and control by other people.

Traditionally, professionals in the field of developmental disabilities have recognized the need for "hard services" such as residential, vocational, and formal support services to a greater extent than they have recognized the need for informal supports. Only fragmented efforts have been initiated relative to the use of informal supports. This has not been the case in other human service areas. For instance, in the field of mental health and aging, the importance of informal support networks has been recognized and efforts have been initiated to assist in their development (Biegel & Naparstek, 1982; Gerhard, Dorgan, & Miles, 1981; U.S. Dept. HHS, 1980)

Types of Informal Supports

Persons with developmental disabilities may receive assistance through one or more of the major types of informal supports shown in figure 3.

The composition of informal support networks will vary from person to person; a person may have no need for a particular type of support. In addition, the composition of a person's informal support network will change during the course of his or her life.

- o Self-Help, Mutual Support Groups: Self-help groups are composed of persons who share a common condition, concern, or experience. These groups are largely self-governing and self-regulating, and generally offer face-to-face or phone-to-phone mutual supports that are accessible without charge. Groups such as People First try to provide participants with a sense of belonging, and recognition that their personal concerns and personal situations are shared by others. A person might regularly attend a support group that meets at a nearby community center.

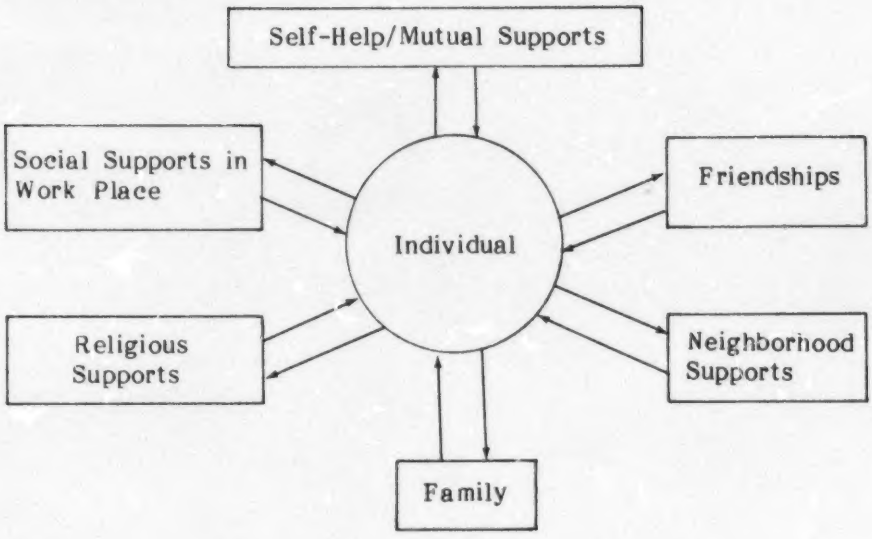
- o Social Supports in the Work Place: Any relationship or peer group identity fosters a person's overall sense of social and vocational belonging. Such relationships enhance a person's social development and quality of life. Co-workers, for example, might informally spend their lunch hour together, or go out after work to a social gathering place.

- o Neighborhood Supports: Persons or families in the neighborhood might befriend the individual and, through their interactions with that person, provide assistance and support. For example, a neighbor might assist an individual in doing minor household repairs, or might invite the person over for dinner.

- o Religious Supports: Friendships and formal, or informal, groups may be organized around religious beliefs that are designed to promote spiritual growth, provide fellowship opportunities and encourage cooperation among members. Participation in a Bible study or prayer group, or a church-sponsored singles group that plans social activities, might provide religious support.

- o Family Supports: Aid and cooperation are given by family members and relatives toward another family member for the purpose of promoting the growth and

Figure 3


Self-Help/Mutual Supports
Social Supports in Work Place
Friendships
Individual
Religious Supports
Neighborhood Supports
Family

welfare of the member, or of the family. An individual might, for example, have a sibling spend the weekend, or a family might have regular gatherings for dinner.

- Friendships: Mutual attachments, companionships, or alliances between two or more people comprise friendship supports. Going bowling or to the movies are activities that can provide opportunities for friendship support.

Obstacles

Certainly there are major obstacles that limit the range of informal supports for persons with developmental disabilities. As previously discussed, one obstacle is societal attitudes, which portray these individuals as deviants. Another factor is the difficulty that persons with developmental disabilities have in developing and maintaining interpersonal relationships. Also, the service system's use of restrictive living, working, and training environments restricts the development of such relationships. However, the evidence suggests that society's attitudes can and do change, that persons with developmental disabilities can be taught social skills, and that normalized living, working, and training environments can be developed.

Early Efforts at Organized Supports

Some early efforts to "organize" informal supports for persons with developmental disabilities are seen in the following programs:

- Parent Support Groups: Such groups assist parents in dealing with the emotional trauma that can accompany the birth of a child with handicaps.

- Citizen Advocacy Programs: One-to-one relationships between a trained volunteeer and a person with developmental disabilities are provided. The volunteer serves as an advocete, and also provides practical assistance and emotional reinforcement (Addison, 1976).

- The Foster Grandparent Program, the Senior Companion Program, and the Retired Senior Volunteer Program: These programs establish relationships between older citizens and persons with disabilities (PCMR, 1977).

- o Training and Support Groups in Parenting: Families in which one or both parents have developmental disabilities, and who have children, are assisted through programs such as Mother's Friends, (Southwest Mental Health, Columbus, OH).

A more recent development has been the emergence of the "Developmental Disabilities Self-Help Advocacy Movement" (Budde, Gollay, & Bennet, 1981). Self-help advocacy organizations, composed of persons with developmental disabilities, have been formed in various parts of the country: People First, Consumer Advocacy Council, and Disabled Alliance of Hawaii (Woodward, 1978). Some of these groups are oriented primarily toward service issues and political action; some are largely social, support groups; and others combine both approaches.

Future Directions

If persons with developmental disabilities are to be integrated into the community, both physically and socially, opportunities must exist to develop, use, and maintain informal support networks. This will require that professionals and the general public recognize the potential of persons with developmental disabilities rather than presume incompetence. This is not to say that persons with developmental disabilities will not require services or supports from the service system, but rather that a balance must be maintained between providing formal services and supports and facilitating access to the informal supports available in the natural environment.

Professionals also must use proven training technologies to help persons with developmental disabilities to acquire the skills necessary to develop and maintain informal support relationships. Training programs must be geared toward assisting persons with disabilities to function more like typically valued people and to be able to function in as many aspects of the valued general culture as possible. Skills must be learned and practiced under the conditions in which they ultimately will be used (Martin, Rusch, & Heal, 1982; Stacy, Doleys, & Malcolm, 1979).

Living, training, and working environments should be designed to foster the development of informal supports. The use of restrictive or segregated settings not only decreases the likelihood of developing appropriate informal support relationships, but also increases the risk of facilitating abnormal behaviors that would reduce the likelihood of establishing informal supports. Living, training and working environments must be as age and culturally appropriate as possible. For example, residential settings must be as similar as possible to other typical residential units in the community: culturally-valued and devoid of

signs that might cause a person with disabilities to be set apart from the community. Likewise, to achieve maximum acceptance it is important that living situations be congruent with the person's chronological age. Living, training, and working environments that are not age and culturally appropriate present a major impediment to the establishment of informal support relationships.

Informal supports for persons with severe disabilities will be difficult to develop. It is not realistic to assume that such supports will be developed without a concerted effort on the part of the "service system" to foster the development and maintenance of such relationships. A variety of models have been developed that reflect greater system involvement, such as personal advocacy, live-in friends, and the companion-model (Addison, 1976; DeFazio & Pealer, 1981; Moreau, Novak, & Sigelman, 1980). Moreover, professionals need to find ways to foster the development of informal support relationships, and to link and support the members of the individual's support network.

The development of informal support networks for persons with developmental disabilities will be difficult to establish; professionals, local agencies, and communities will have to reassess their traditional roles in assisting persons with developmental disabilities to live in the community. However, such relationships are possible and are being developed in various communities around the country (PCMR, 1978; Perske, 1980). Developing an expanded knowledge of informal support networks for persons with developmental disabilities is a first step in this direction.

FORMAL SUPPORT SERVICES

RECOMMENDATIONS

- **A full range of formal support services should be available at the local level (county or multi-county) to meet the multiple needs of persons with developmental disabilities.**

- **Community generic agencies and resources should be used, as much as possible, to ensure the person's presence and participation in community life.**

- **Planning for, and the delivery of, formal support services to persons with developmental disabilities should reflect joint or multi-agency involvement at the local level (county, or multi-county).**

- **Direct consumer participation should be an integral part of local planning and service delivery for persons with developmental disabilities. Local agencies should**

develop policies that ensure direct consumer involvement, and should encourage such involvement.

- o Preservice and inservice training programs for professionals and paraprofessionals should be available to reflect the use of generic support services.
- o Adequate funding should be available for formal support services, and funding mechanisms should be flexible to allow for the use of a variety of local service agencies.
- o Education programs for County Boards of MR/DD personnel and board members should be designed to foster the use of generic community resources.
- o Training and technical assistance programs should be available to assist community generic agencies in serving persons with developmental disabilities.
- o Education and assistance programs should be available to parents and families of persons with developmental disabilities (especially of younger children), and to parents with developmental disabilities who may also have children, to encourage and foster their use of a full range of community resources.
- o Inter-agency coordination efforts at the state level should ensure optimal coordination among local agencies and reduce barriers to local cooperative efforts.
- o An empowered case coordination system should exist at the local level to maximize the use of a full range of local services. Adequate salary levels and training programs should be provided that reflect the importance of case coordination.

INFORMAL SUPPORT SYSTEMS

- o A range of informal supports for persons with developmental disabilities should exist in the community.
- o Education and training programs that create awareness and provide skill development in identifying and fostering supports for persons with developmental disabilities should be provided for planners, administrators, professionals, and paraprofessionals.
- o Funding should be provided to encourage the development of a body of knowledge on informal supports for persons with developmental disabilities.

Recommendations

- o Living, training, and working environments should foster the development and maintenance of informal support networks.

- o Professionals and paraprofessionals in the field of developmental disabilities should:

  (1) Assist persons with developmental disabilities to develop the skills necessary for creating, maintaining, and sustaining informal support relationships

  (2) Encourage the development, and nurture the continuation of such relationships

  (3) Be available to provide assistance as needed to members of the informal support networks

  (4) Be careful not to overextend their involvement in informal support networks

PUBLIC EDUCATION

- o Public education awareness programs should exist that emphasize the "sameness" of all persons, including those with developmental disabilities.

- o Adequate funding should be allocated for public education awareness programs.

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